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ABSTRACT

Respite and in-home services have been identified by caregivers as vital for maintaining a frail older person in the community. A program called The Alzheimer Support/Tender Loving Caregivers Project was undertaken in northwest Indiana to strengthen the informal support network of disabled elderly in the community. An interfaith coalition of churches and a mental health center recruited and trained volunteers, identified impaired older persons and their families, and matched volunteers to need. Volunteers were instructed in providing respite, referral, and advocacy services to frail, homebound elderly and their families. To evaluate the program, descriptive data were collected from individuals attending training sessions, volunteers, caregivers, clergy/volunteer coordinators, and mental health professionals. Knowledge level after training, volunteer attrition and services, caregiver interviews, and coordinator interviews were used to rate and track the effectiveness of the program. Results showed that: (1) training increased knowledge and was favorably assessed by participants; (2) support groups were self-contained; (3) church congregations benefited from the educational component; (4) services were provided to 44 noninstitutionalized persons, most of whom were not church members; and (5) most service requests were handled informally although a formal interview was also used. Seventeen months was considered sufficient time to begin the coalition, recruit and train volunteers, and develop support groups. (Recommendations for replicating the project are included.) (ABL)

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Church Based Counseling Services for Older Persons with Alzheimer's Disease and Their Families

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STATEMENT OF PROBLEM

PROJECT ABSTRACT

Church Based Counseling Services for Older Persons with Alzheimer's Disease and Their Families is a model for coordination between the formal and informal service delivery system. Congregations in Northwest Indiana, a university and a community mental health center formed an interfaith coallition to develop the Alzheimer's Support Project and the Tender Loving Caregivers program to meet the needs of frail elderly and their families through several services provided by trained volunteers.

The first service is a seven-session volunteer training program covering such topics as normal versus abnormal aging, Alzheimer's Disease and Related Disorders, helping skills, volunteer duties and responsibilities and caregiving techniques to employ while providing respite care. Followup inservice training and consultation to congregation volunteer groups is ongoing after the completion of the training series and the implementation of a Tender Loving Caregivers program in a congregation.

The second service is a volunteer visiting program initiated through the congregations reaching frail elderly in their homes, homes of adult children or in nursing homes in order to provide visitation and respite for caregivers.

The third service provides caregivers support groups that are co-facilitated by professionals and volunteers, meet in congregations and are open to the community. Mental health staff provide assessment and referral of families for respite care, support groups or other community services.

Finally, the project provides community education and awareness of the issues related to Alzheimer's Disease and Related Disorders through distribution of newsletters for volunteers and caregivers and planning of media presentations, professional workshops and conferences attended by caregivers, volunteers and professionals in the aging network.

A model for church based services for Alzheimer victims and their families: interface with a social service agency

Introduction Contrary to pervasive myths of filial neglect of aging parents, families have been the primary source of long-term care for impaired older adults. When institutionalization does occur, the exhaustion of family resources, including the ability to cope with caregiving, or the absence of family, have been key predictors (cf. Colerick and George, 1986; Pett et al, 1986). Surprisingly, the level of disability of the senior, and other patient variables, have not been the significant factors in the decision to institutionalize (cf. Fitting et al., 1986; Kiyak et al, 1986; Colerick and George, 1986). Thus interventions aimed at deterring unnecessary institutionalization have stressed material and emotional support to the family in continuing in their caregiver role. Specifically, respite and in-home services have been identified by caregivers as vital for maintaining a frail older person in the community (Caserta et al., 1987). The same type of services, provided at a more intense and comprehensive level can also enable a vulnerable older adult without social supports to avoid inappropriate nursing home placement.

The Alzheimer Support/Tender Loving Caregivers Project has been among a few innovative programs which utilizes volunteers to strengthen the informal support network of disabled elders in the community. A mental health center, in collaboration with an interfaith coalition, recruited and trained volunteers, identified impaired older persons and their families, and matched volunteers to individuals in need. Seven training sessions were offered within each of 7 congregations, in which recruited volunteers were instructed in providing respite, referral and advocacy services to frail, homebound elderly (particularly those afflicted with Alzheimer's disease) and their families. Once training was completed, volunteers were organized in church-based groups which would provide assistance to elderly congregants so as to deter unnecessary institutionalization. Volunteers were expected to provide respite for caregivers needing a break from the onerous responsibilities of care. If they chose, volunteers could become secondary caregivers, selecting those tasks they would be willing to periodically or regularly perform such as transportation. In addition, support groups for caregivers were started in congregations.

Method of evaluation Descriptive data were collected from individuals attending training sessions, volunteers, caregivers, clergy/volunteer coordinators and mental health professionals through a variety of methods. Questionnaires administered to volunteers before the initial training session provided a demographic profile of participants and baseline data on knowledge and attitudes towards Alzheimer's disease, the aging process, and related issues. Questionnaires administered after training was completed determined knowledge acquisition, attitude change, and the effectiveness of training modules. A monioring process which tracked client and volunteer attrition through logs kept by volunteers, volunteer coordinators, and the program coordinator at the mental health center provided a continuously up-to-date list of active program participants, services provided and referrals made. Interviews with caregivers, and short functional and mental status assessments of impaired older adults were used to retrieve data on (1) characteristics of the population assisted (2) degree of impairment of seniors (3) the caregiving role and associated feelings of

burden and (4) utilization of formal services. Re-interviews at the conclusion of the program gauged the amount of change on these dimensions that might be attributable to program intervention. Clergy/volunteer coordinators and mental health professionals were interviewed about the perceived impact of the program on the participants, congregations, and the mental health center. Meetings of the support groups affiliated with the project were observed.

Findings The overall goal was to link the formal and informal service delivery systems utilizing congregation volunteers, mental health center staff, consultants from local universities, and other professionals in the aging network. Findings indicate that the overall goal was reached because of evidence of project impact in five areas of investigation:

* Training of volunteers. The main findings from the evaluation of the project's training sessions were derived from questionnaires and telephone interviews. 116 persons attended at least one of 7 sessions sponsored by the project; nearly 40% attended 6 or more of the sessions. There was a preponderance of older, non-working women, a large proportion of whom are not married. While the majority of those attending training were members of the congregations at which training sessions were held, nearly one-quarter were not. Trainees were found to have extensive background or current engagement in volunteer activities. A large proportion of these activities were connected with the church or religiously affiliated organizations. Very few however had been or were currently involved in volunteer activities connected with older adults. Only a minority of participants in training intended to become volunteers for the program. The training sessions drew caregivers and other interested congregants who did not commit themselves as volunteers during training. Knowledge of Alzheimer's disease possessed by participants prior to training was impressive. Nevertheless, an increase in knowledge following the seven training sessions was demonstrated. Levels of knowledge on other topics of aging were equally impressive preceding training. No increase in knowledge in these areas was observed. An overwhelming majority of participants favorably assessed the training program.

*Support groups. The two support groups that developed within the project were evaluated through observations of six meetings of each of the support groups and interviews with facilitators. The two groups represent different models, with one providing an outlet for emotional expression by spouses of Alzheimer victims and the other providing information and mutual support to children of older adults. What the two groups did have in common was their relationship to the parent program. The support groups became discrete entities with distinct identities within the project. There was minimal movement from the support group to other facets of the project. Moreover, the groups were self-contained within the churches in which meetings were held. Most participants were not members of the host churches nor of any of the churches in the interfaith coalition.

*The role of the church in service provision. Interviews with congregation coordinators revealed that the main benefit of the program to congregations was education. Of the seven congregations which were involved in the interfaith coalition, 3 participated in only the training component of the project. In the four remaining congregations, 3 distinctive program models evolved, which were divergent in focus, organization and placement within the church infrastructure of volunteer

initiatives. In one model, a pre-existing volunteer organization in the congregation utilized training to sharpen the skills of its members in dealing with elderly congregants, neighbors, or family members. In the second model, a new program was created, but it required extensive support because of difficulty enlisting volunteers and recruiting famiies to be served. Grafting the program onto the congregations was a major feat because of the program's detachment from other lay ministries and because the exchange of informal assistance between congregants outside the lay ministry was not the norm. In the third model, a new program was launched which became successfully institutionalized within the church. Its success was due to its lay and clergy leadership, its links with other congregation-based or community-based religious organizations, its systematic approach to identifying need and providing service, and the vast collective experience of its volunteers. However, meeting the spiritual needs of nursing home residents replaced to a large degree the project goal of material assistance to the homebound.

*Volunteer activities. The success of the TLC program in recruiting volunteers to offer temporary relief to caregivers and/or other services was examined through a telephone survey of volunteers. Twenty-one volunteers were identified from among 42 persons contacted. The volunteers were differentiable from the rest of the persons who underwent training by their volunteer experience, their completion of the training series, and their early commitment to the program. A total of 55 services (of seven different types) were provided by volunteers, with the majority of volunteers providing more than one service. Most services were provided on an ongoing basis to 44 noninstitutionalized persons. Only a small minority of volunteers served exclusively congregants of their church. Assistance to indivdiuals outside the congregations has been found to be a feature in other interfaith volunteer programs (cf. Holloran, 1987; Lewis, 1987).

About one-half of the volunteers had at least some negative experiences or ambivalent feelings, even though they continued to provide service because of a sense of religious duty. Dissatisfaction with the experience revolved around disappointment with the lack of manifest appreciation for their work by cognitively impaired older persons and uncertainty about the amount of assistance that should be offered to older persons and their families. The findings are consistent with those of Montgomery and Hatch (1985) in their study of a volunteer respite program. Without exception, volunteers were enthusiastic about the training they received and its utility in their volunteer experience. A majority of respondents had shared the information they learned with others.

* Family caregivers and impaired older adults. Family caregivers who applied for assistance from the program and were referred for assessment were asked to participate in a 45 minute interview conducted by mental health staff as they entered the program. The interview was administered again after nine months to gauge changes. Most congregations, however, chose not to refer families for assessment but rather handled requests for service informally. Only fifteen caregivers and one older adult living alone in the community were assessed for the TLC volunteer program. The data reveal that the majority of respondents were white, non-working females caring for Alzheimer sufferers, neither of whom were members of the congregations of the TLC coalition. The families varied considerably in terms of the extent of caregiving responsibilities, number and type of behavioral problems encountered, their perception of burden and willingness to institutionalize. Formal service utilization was uniformly low but most

caregivers shared their responsibilities with other members of their informal support network. One-half of the families undergoing assessment were not interested in volunteer services. Instead, they were seeking information and referral, support group, or emotional support services from mental health center staff. Within the nine month period, one-quarter of the families had utilized the volunteer respite services, and utilization was on a sporadic basis. Services were provided in general, in a context of intensifying behavioral problems and increasing caregiving responsibilities.

Implications and Recommendations When other communities explore the possibility of implementing this project, findings from this demonstration project will enable them to select reachable goals within a given time span. In general, it was found that seventeen months is sufficient time to begin a coalition of churches, initially recruit and train 20-25 volunteers in 4 congregations serving 40-60 older adults who are homebound or in institutions and develop support groups. Seventeen months is not sufficient time to begin an entirely new volunteer program within a congregation with a full range of services, identify and train volunteers to provide overnight respite, and familiarize community families with the service so that they will select it.

The recommended steps in replicating the project would be as follows:

(1) Congregations which would be most suitable for joining a coalition are those which have a mission of providing tangible assistance to congregants, clergy and lay leadership for a program of this sort, and an interest in serving older adults and family caregivers. The process is made easier if there are existing lay ministries in which the program can become incorporated. Projects can begin in congregations where volunteers are not already organized to visit the homebound, but it takes longer to implement the program in such congregations.

(2) Identifying needs in the community is an essential ingredient of the development of the goals of any interfaith coalition. The group can prioritize unmet needs that volunteers can meet. All congregations in the interfaith coalition have to agree upon two or three basic goals, but variation in implementation is to be expected and is desirable for cross-fertilization of ideas. Goals should be set that take into account funding contingencies, are time-limited, and are adaptable to the changing availability of resources. From the beginning, congregations should have a vision of what will occur after the original interfaith coalition project is completed.

(3) Selecting key people involves recruiting members for the advisory committee, hiring project staff, identifying consultants familiar with the issues of aging, and seeking financial resources from appropriate local, state, and national funding sources.

(4) Community education is one of the first public efforts of the advisory committee to alert the community at large of the needs of Alzheimer's patients and their families. Techniques to spread the word about the project, such as special church services, church bulletins, special newspaper articles, will reach potential volunteers and care recipients early in the project development.

(5) Churches clearly are a comfortable setting in which to disseminate information. However, recruiting sufficient numbers of volunteers to begin a program requires training three times as many individuals as are demanded of the program. It is to be expected that caregivers will attend training,

though they do not intend to volunteer at this time; consequently training sessions should be adapted to their needs. Because knowledge levels about Alzheimer's disease and nonpathological aging appear to be high prior to training, an emphasis on attitudinal change and experiential learning is desirable. Since the training is likely to attract experienced volunteers, publicity efforts for training should be aimed at existing volunteer church and community groups.

(6) The decision to begin a support group is determined by several factors. The number of already existing support groups in the vicinity, the past history of the congregation to provide counseling support, the availability of lay and professional leadership willing to facilitate the group over time, and the number of families seeking this type of service will affect whether a support group emerges in each congregation. Support groups can operate independently from the parent project and develop their own models. Support groups may be selected by caregivers independently of selecting any of the other project components (volunteer visitation, training).

(7) Integrating volunteers into the program is vital because of the nature of the work and lack of intrinsic rewards in working with cognitively impaired elderly. Volunteer meetings, honoring ceremonies, newsletters, and contact with mental health staff can support and socialize the volunteers. Nursing home visitation can be a means of introducing the volunteer to the experiences they will encounter.

(8) Matching volunteers with families in need may be done through informal channels. Congregations can expect most linkages to be made without an assessment by an intermediary social service staff person. Some families will need an assessment and clinical intervention because of the extensive nature of their problems. More than one volunteer may be necessary to meet the needs of a family. On the other hand, families may seek primarily the education, information and referral and support services of the program. Efforts need to be directed to clarifying the responsibilities of the volunteer with any given family and to overcoming resistance by families to accepting assistance. Coordinators must expect that volunteers may not keep records of activities because they perform tasks out of a sense of religious duty.

(9) Since record-keeping may not be consistent across congregations, a simple monitoring system must be designed at the outset of the project. At a minimum, the project should track both volunteers and care recipients through their involvement in the program and assess whether the proram is fulfilling its goals according to a pre-established timeline.

The steps outlined above are presented in greater detail in "Tender Loving Caregivers: How-to manual on developing congregation based services for older adults and family caregivers."

Future of the project When the demonstration project ended in February, 1987, the advisory committee decided to continue meeting on an alternate monthly basis. The clergy and volunteer coordinators of the committee will continue to give direction to the project and reformulate goals given new funding from the Indiana Department on Aging and Community Services for fiscal year 1988, beginning July 1, 1987. The funds will support two-thirds of a consultant in the Consultation and Education Program of the mental health center for the purpose of project maintenance, training, and

consultation to existing TLC projects in the community. The advisory committee will prioritize project objectives in light of limited funding.

Enthusiasm about serving older adults has continued. The various participants in the program have chosen to remain involved.

* Congregation coordinators accept referrals for care and develop methods to deliver much needed services with limited resources. It has been found that some older adults live in senior high rises and need visiting services. Though they are technically living on their own, adult children must visit them daily to maintain these apartments. The constant supervision by children at a distance places an enormous strain on these caregivers. Therefore, a coordinator in the program has initiated a visiting service in one of the buildings to reach two older adults who may be suffering from an early stage of Alzheimer's disease. The coordinators have collaborated with the high rise manager, nutrition site manager and caregivers to delay institutionalization. In addition, project staff and coordinators are jointly assisting another elderly person in her own home who presents a multitude of problems and needs many services to maintain her independence in the community.

* Congregation volunteers visit frail elderly in their homes, relatives' homes or nursing homes. They call by phone, provide transportation, conduct group activities, and bring religious services and celebrations. They support caregivers through the same services and become, in some instances, one of the only supports outside the family. Volunteers receive inservice training and consultation on an ongoing basis from project staff.

* Project staff employed by the mental heatlh center co-facilitate support groups, assess families, provide short-term crisis counseling and train volunteers. Consultants, staff and volunteers are beginning the second year publishing two newsletters (one for volunteers entitled "TLC Newsletter"; one for caregivers entitled "Caregivers Update"). Furthermore, there have been additional requests from training indicating an increased awareness in the professional community.

The culmination of the demonstration project and research efforts was the writing of a how-to manual so that other communities can replicate the program. The manual is entitled "Tender Loving Caregivers: How-to manual on developing congregation based services for older adults and family caregivers," and will be available through the Consultation and Education Department of Tri-City Mental Health Center.

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